



# Area Connection

## June 2007



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## Your Day, Your Way!

The SCDD/Area Board 6 protects and advocates for the rights of persons with developmental disabilities in Amador, Calaveras, San Joaquin, Stanislaus and Tuolumne counties.

The State Council recently presented a groundbreaking report recommending changes in the adult service system to Governor Schwarzenegger and the State Legislature. This report, called ***Your Day, Your Way! Expanding Opportunities and Choice in California's Day Program Service for Individuals with Developmental Disabilities***, reflects the insights of stakeholders in the adult system, including people who use services, family members, service providers, advocates, and state agencies representatives.

### Policy-making Alert

People who use services and their families have an essential role in shaping the service system. Before policy ideas become law and regulation, the public has a chance to add ideas and suggest changes.

Right now, the **State Budget** is being decided. Comment is sought now on **changes in IDEA** for children up to age of 3; **autism services** in California; and **CA Department of Rehabilitation regulations** on supports to help people start their own businesses. (cont on page 2)

### 10 Recommendations from SB 1270 Stakeholders

1. Make sure people with developmental disabilities and their families get information about integrated employment, community participation, work and health benefits at IPP meetings.
2. People have their own self-directed service budgets, decide on the kinds of services they want, and buy their services.
3. The State Council will ask state agencies like DDS, Department of Rehabilitation and the Department of Education to put funding together to help people with developmental disabilities and their families figure out what to do after high school.
4. The State Council will work with its State Public Agency partners and all employers to hire more people with disabilities.
5. Help individuals who have good ideas about work/job services or community services and people with developmental disabilities who want to start their own business

(Cont on page 7)

#### Board Members

**Gary Del Nero, Chair**  
Governor Appointee  
Stanislaus County

**Governor Appointee**  
Brad Putz  
Tuolumne County

**Amador County**  
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Anna Newman

**Calaveras County**  
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**Stanislaus County**  
Traci Trujillo  
(vacancy)

**Tuolumne County**  
Jill Ames  
Dierdre Wright



**The Advocates** Rock SJ  
County Fair - see their story, pg 2.



### Policy-making Alert - cont from page 1:

**New regulations have been proposed for Part C of the *Individuals with Disabilities Education Act (IDEA)***, to make it more consistent with the rest of the Act. Part C covers services to infants and toddlers through age 3, who have or are at risk of developmental delays. Comments must be received by **July 23, 2007**. To see the proposed regulations and comment, go to <http://www.idea.ed.gov>.

**The California Legislative Blue Ribbon Commission on Autism** has been holding public hearings on task force reports for supports and services to children and young adults with autism. The Commission was established to identify service gaps and recommend solutions related to the early identification of autism spectrum disorders. Their first focus is on Early Identification & Intervention; Education & Professional Development; and Transitional Services & Supports. To contact the Commission, write them at 1020 N Street, Room 359 / Sacramento, CA 95814. Phone: (916) 319-3541; or e-mail to: [Autism.Commission@sen.ca.gov](mailto:Autism.Commission@sen.ca.gov).

**The Department of Rehabilitation has issued proposed regulations on self employment.** Proposed regs still significantly limit supports available to people with developmental disabilities. Full text of the regs are available from Area Board 6, at 209-473-6930. Comments must be received by **July 2, 2007** at: DOR Regulations Unit, 2000 Evergreen Street, 2nd Floor / Sacramento, CA 95815-3832, or emailed to: [jloyola@dor.ca.gov](mailto:jloyola@dor.ca.gov).

**BUDGET INFO AVAILABLE at Legislative Analyst Office ([www.lao.ca.gov](http://www.lao.ca.gov)), DDS ([www.dds.ca.gov](http://www.dds.ca.gov)), and California Disability Community Action Network ([www.cdcan.us](http://www.cdcan.us)).**

### Cont from page 1 **THE ADVOCATES**

In the seventh year of musical productions, a small group of performers have taken their act on the road. *The Advocates* sing and perform 45 minute shows. They've delighted crowds at the Asparagus Festival in Stockton, the Choices 2007 Conference, and San Joaquin County Fair.

Future shows include the Stanislaus County Fair on July 31, 2007 and a Holiday Show at the Stockton Civic Auditorium on December 11, 2007. For more information about the group, please contact their band manager Nancy Dacumos at (209) 466-2448.



### **More than just a job:**

### **Lodi Man is Guest Services Supervisor For Lodi Stadium 12**

"Working hard and doing my best" led Steve Boddy to his position as Supervisor of Guest Services at Lodi Stadium 12 Theater. "I like supervising others and leading by example," Boddy added. Boddy began working as an usher at theater 3 years ago. A year later, he was promoted. He instructs other employees on hospitality and insures that patrons are treated properly. He also makes sure that the theater meets cleanliness standards.

Boddy found his job with help from ARC of San Joaquin employment services. Eight months of their targeted job development led to a position ideally matched to Steve's strengths. "Steve likes to greet all people with a handshake and a smile," said Art Gomez, Vocational Services Program Director. ARC SJ also works closely with Boddy's employer to make sure work communications are clear. Supported Employment services provide follow-along support as long as the person has the job. "I look forward to more of these stories for others too," said Cindi McKnight, Director of ARC SJ.

### **Home Ownership, Country Style**



Harold Junior Tucker, or Junior to people in Tuolumne county, has a goal of paying off his home mortgage. Junior and Janet, his wife of 19 years, bought their two bedroom home in 1994. They were helped by WATCH, an agency

serving people with developmental disabilities in Tuolumne county.

Junior also works on a landscaping crew. "I always want outdoors in my life," he declares. But of most all, Junior says "What I want to be known for and what I am most proud of is my hard work and honesty."



**At the May 22, 2007 public meeting, the Area 6 Developmental Disabilities Board voted to support Exceptional Parent (EP) Magazine's Position Statement :**

**When the Slippery Slope Becomes a Mudslide,**

prepared by Joseph M. Valenzano, Jr., CEO and President;  
Rick Rader, MD, Editor In Chief; Tricia Luker, Editorial  
Director-Organizational Relationships ; Jan Carter  
Hollingsworth, Managing Editor

In its thirty-six year history, *EP* magazine has rarely taken a position in areas of controversy or differences of opinion. We prefer, as a matter of journalistic principle, to present objectively all sides to a given argument and debate, adhering to our mission of providing credible information for and on behalf of those involved in the care and development of children and adults with disabilities and special needs.

We have, however, taken a rather strong stance on issues such as: extending the benefits of the Orphan Drug Act, condemning a policy that endorses the use of restraints, and supporting the expansion of newborn screening utilizing tandem mass spectrometry (MS/MS). We thought long and hard about taking stands on these issues, and we did what we felt was the right thing. Now we find ourselves met with yet another great challenge the very essence of human life and dignity and our conscience dictates we do the right thing once again.

In January, the story of Ashley and her "treatment" burst out in the national news. Ashley, who is now nine years old and has significant and lifelong disabilities, was given "growth attenuation" surgery and medication when she was six years old to keep her from growing to a full adult size. Her parents, in a decision that they say in their website "was not difficult," found physicians willing to surgically remove Ashley's breast buds, her appendix (even though nothing was wrong with it), and her uterus. She was then treated with high doses of estrogen to stunt her growth. These procedures were performed without either court or ethics committee approval. Indeed, the institutional ethics committee that the family and physicians consulted prior to placing Ashley under the knife, decided to leave the decision in the parents' hands, rather than engaging in the comprehensive, ethical debate the procedure deserved. As one might expect, the

story of the "Ashley Treatment," the name the parents themselves coined for the procedure, generated brief but bitter debate.

Things have now quieted down again. Barely three weeks after Ashley's story hit the press, Switzerland's Supreme Court, to virtually no groundswell of public outcry and very little public notice, ruled that it is now permissible in Switzerland to allow assisted suicide for persons with serious mental illness, even if their condition is not otherwise terminal. Switzerland already permitted assisted suicide for people with terminal illnesses at the time this decision was announced.

The "Ashley Treatment" and Swiss assisted suicide stories came along about 15 months after a Netherlands facility announced the creation and implementation of the "Groningen Protocol." The Groningen Protocol, named for the pediatric hospital at which it was devised, described a five-step process physicians are encouraged to follow to sanction the euthanizing of infants who are born with serious, potentially life-threatening disabilities. The end step in the Groningen Protocol is that the physicians inject medication to kill the infants, rather than letting the infants pass away as a result of their disease or defect running its course. The Groningen Protocol physicians, at the time announcing the Protocol, also announced that they had implemented the Protocol to euthanize four infants even before the Protocol was announced. One of those was a child with Down syndrome. Despite the implications of what the Groningen physicians call "a deliberate, life-ending procedure," the story received no substantive coverage in America outside of the medical community.

The deafening silence now accompanying the not-so-subtle threats that people with disabilities face because of procedures like "Ashley's Treatment," mental illness based assisted suicide and infant euthanasia is appalling. Ashley's story emerged three years after the major part of her surgery had been completed. Four infants were euthanized using the "Groningen Protocol" before the public even knew the protocol existed. How and why does this happen? And why does the Ashley story suddenly surface?

History has shown us that children with disabilities have been victims of involuntary sterilization, institutionalization, and widespread (cont on pg 6)

# Financial Resources

What are some examples of financial resources available to individuals with developmental disabilities and their families? First are the resources that may be provided by Social Security, the educational system and the local regional center.

**Social Security benefits** are available to children and adults with disabilities. There are different social security programs. Each program has its own rules about who qualifies and how much financial assistance is provided. Some benefit programs are based on wage earning by the individual or by parents, and some are based on financial hardship. A child can be considered a household of one, even when living with family, if the child is "institutionally deemed" (see *Medical Resources*, pg 5), saving medical expenses. Eligibility for Social Security is also used by other agencies to help determine whether or not the individual qualifies for their services.

**Education** is responsible for providing educational services to children with disabilities who are served through the Individual Educational Program (IEP) process. These services can sometime reduce costs that families would otherwise have to pay to meet the needs of their child. For example, schools may be responsible for preschool education and extended school years. Community colleges offer a variety of disabled student services, including some employment opportunities.

**Valley Mountain Regional Center** funds services and supports identified in the Individual Program Plan for their clients, or assists their clients to get help from other resources. For example, VMRC could pay for the cost of diapers for a child who is past the typical age for needing them. Valley Mountain Regional Center serves the mountain counties of Amador, Calaveras and Tuolumne (209) 754-1871. San Joaquin County (209) 473-0951, and Stanislaus County (209) 529-2626.

## Getting Services

Services are provided through a mix of public and non-profit organizations, relying on a combination of public and private funding. Organizations "major" in specific service needs, like employment or adult education. Each has its own rules about who can qualify. Even their own staff may not know the details of all their own services! How can you make sure that you and your family member are getting all that's available to meet your needs? Advocacy resources can sometimes be your best bet.

**Area 6 Board:** 209.473.6930 [www.areaboard6.ca.gov](http://www.areaboard6.ca.gov)

**Disability Resource Agency for Independent Living:** San Joaquin -(209) 477-8143; Stanislaus—(209) 521-7260; Mountain Counties - (209) 532-0963 [www.drail.org](http://www.drail.org)

**Disability Benefits info:** [www.DB101.org](http://www.DB101.org)

**Family Resource Network:** 209.472.3674 or 800.847.3030

**Medical Benefits Counseling, HICAP:** 800.510.2020

## More tips:

Some programs, like Meals on Wheels, serve adult dependent children of seniors. Private medical insurers will also sometimes extend coverage to adult children who are disabled. If you're a parent of a child with special needs, remember to check on the benefits that you have to see if your child is also covered.

Don't ignore free offers from financial institutions. Some credit unions assist with burial costs if a member's child passes away.

Become networking savvy! Connect with other families and people who use services through CAC's, parent support groups, self advocacy groups and websites. Always remember that someone else's story may or may not apply to you - and always check the facts for you and your family.

We're in a national health care crisis, as costs rise and needs increase. Many families struggle with finding specialists that their children need, or to find medical resources that accept Medi-Cal patients. New citizenship ID requirements impact on access and costs. According to the Disability Health Coalition, a coalition of organizations working to increase health care access for people with disabilities, more than 1 in 4 Californian adults lives with some kind of disability. 1 in 5 working age Californians with disabilities have no health insurance at all. Right now, state policy-makers are working to find solutions for Californians. News is available at Governor Schwarzenegger's Stay Healthy California issue page ([www.stayhealthycalifornia.com](http://www.stayhealthycalifornia.com)), California Foundation for Independent Living ([www.cfile.org](http://www.cfile.org)), and California Disability Community Action Network ([www.cdcan.us](http://www.cdcan.us)).

## Disability Health Coalition Statement

### HEALTH CARE REFORM FOR PEOPLE WITH DISABILITIES MUST:

#### **Remove Barriers to Physical & Programmatic Access:**

People with disabilities must be able to use all health care facilities, services, and programs. Health care facilities must provide accessible exam and diagnostic equipment to ensure quality care for people with disabilities. Health plans and health care providers must be held accountable to federal and state laws that prohibit disability discrimination and require access and accommodation.

**Guarantee Integrated Long-Term Care:** Fully funded, community-based, long-term care must be available in the home to support personal independence and family life. Services and medical supplies must not be limited by "homebound" requirements.

**Provide Durable Medical Equipment & Assistive Technology:** Provide appropriate devices that allow consumers to independently engage in home and community activities. Providers must assist with selection and use of devices.

**Coordinate Chronic Care Services:** Health care services for people with disabilities are often disjointed. To increase continuity, a multi-disciplinary team approach must be used to coordinate the multiple services and providers needed by consumers.

**Eliminate Work Disincentives:** Health care must be designed so people with disabilities do not have to choose between working and maintaining continuous, comprehensive health care.

**Promote Wellness:** Reform must invest in health promotion and disease prevention efforts that account for the diverse needs of people with disabilities, including the prevention of secondary conditions. People with disabilities should have access to specialists and choice of providers.

**Guarantee Mental Health Parity:** Reform must commit to assuring mental health coverage at the same level as physical health coverage.

**Ensure Affordability:** Prescription drug coverage, premiums, deductibles, co-pays, and other out-of-pocket expenses must be affordable.

For more info, contact the Coalition at (916) 325-1690.

## Medical Resources

**In Home Supportive Services (IHSS)** funds care workers to provide personal and household care services to individuals in their own homes. IHSS is available to people who meet requirements based on living situation, income, disability, need for assistance and ability to benefit. Individuals may be eligible for IHSS "protective supervision" services if they are likely to injure or endanger themselves if left unsupervised, even when still living with family. IHSS is available through county Human Services.

**Medicaid Waiver Institutional Deeming (ID)** enables consumers under the age of 18 to get the Medi-Cal coverage without a share of cost, regardless of family income. When approved for Medi-Cal via Institutional Deeming consumers of regional center services can have access to all Medi-Cal services including medical, dental; Home Nursing; Occupational Therapy; Physical Therapy; Speech; Communication Devices; Medical Equipment; Nutrition Counseling; Mental Health; and Therapeutic Behavioral Services. Services must be deemed medically necessary and provided by Medi-Cal approved providers. Participation is voluntary.

**Medicare** is typically medical coverage for adults who are older than 65. Children and adult dependents may also be eligible for Medicare if a parent is receiving Medicare, or is deceased.

**California Children's Services (CCS)** provides medical case management, physical/occupational therapy services and financial assistance for children with certain healthcare needs, including cerebral palsy and some orthopedic disorders.

**When children don't qualify for medical care through Medi-Cal or Medicare, the Healthy Families Program can provide low cost insurance for health, dental, and vision coverage. Call 1-800-880-5305 for more info.**



(*EP Magazine Position Statement, cont. from page 2*) abuse, neglect, and death. Historically, society had little or no expectations for children with disabilities, and their families frequently felt shame. In the last 50 years, parents and professionals have united to reject these inhuman practices and to insist that our children have the same opportunity for lives of dignity and achievement that we expect for ourselves. *EP* magazine has been a leader in fighting to preserve the human dignity of life itself a life we all share, regardless of the existence or degree of disability we might encounter individually.

These dramatic news stories do not represent isolated instances of hard choices in hard times. Each story represents a conscious attempt to expand the number of life-ending or life-altering procedures available to physicians and parents who would choose to use them and, in so doing, rob the child of her or his human dignity. The creators of these procedures want them to be adopted and used by physicians and families throughout the world. The utilitarianism they promote in the name of compassion is nothing other than new language and new ideas designed to encourage the systematic denigration of those with disabilities, stripping them of the basic human right to life and dignity. Over sixty years ago, millions died to rid the world of people who perpetrated these same shameful acts in the name of bogus science. Have we now ignored that sacrifice and the lessons they taught us?

It is an outrage that no court or ethics committee engaged in the soul-searching debate a procedure like "Ashley's Treatment" should have generated. It is an outrage that society should countenance extreme surgical procedures and hormone injections as a solution to the challenges of caring for a six year old with complex disabilities. It is a shame and an affront to the human dignity of every one of us to permit these procedures on even one child. We need to make it right and make sure it never happens again.

We are heartened that so many organizations within the disability rights movement in America have acted swiftly to condemn "Ashley's Treatment." Their actions are justified on several fronts. But we all must become more zealous in our efforts to expose and condemn all similar affronts to human dignity posed by practices like the Groningen Protocol and the use of assisted suicide to address serious mental illness. We see "Ashley's Treatment," the "Groningen Protocol," and the Swiss assisted suicide decision as thinly veiled attempts to objectify and desensitize the value of human dignity. It should never be acceptable in America for a care-providing parent or guardian to authorize and procure "Ashley's Treatment" for a child and have the decision be "not difficult." The difficult action, and the action we at *EP* choose to take, is to fight for the human dignity we all have the right to possess. Taking that away should not just be difficult; it should be impossible. And it should make us all angry that these efforts to strip human dignity are happening all around us in relative secrecy. We cannot let these stories fade away or our dignity fades away with them.

We need to be ever mindful of the words "all that is needed for evil to prosper is for good men to stand by and do nothing." Please, for our children's sake, their children and generations to come, let us not stand idly by. Let us do something. We urge the following:

- *EP* calls upon all professional medical, dental, and other health care related organizations, associations, and societies to come forward with a statement denouncing these treatments and sanctioning those who take part in it.
- *EP* asks private foundations as well as federal and state agencies and departments to consider cutting off all grants to those hospitals or institutions that allow such procedures to take place.
- *EP* calls upon all of science and medicine to denounce publicly the Groningen Protocol, Ashley Treatment, and the Swiss decision on assisted suicide.
- *EP* encourages all disability organizations that have not yet issued statements to join with us in this effort.

## *Your Day, Your Way:* **The Local News**

**Family Resource Network's *Moving Forward* project was awarded a \$5000 mini-grant** from the Area 6 Board, to provide training and support to students aged 15 through 22 and their families. The project goals include producing guides to help students and families explore local adult support options, and to clarify the steps students and families need to take to use those services.



**Stanislaus Transition Task Force** will begin meeting on Monday, July 23, 10 am —12 noon, in the SELPA Community Room, on the JFK Campus. **Individuals and agencies interested in transition from school to adult life for students with disabilities are invited to participate.**

The Task Force goals are:

- \* Information sharing about current services and future planning;
- \* Improved coordination of services and supports;
- \* Training on best practices;
- \* System change in response to the enlarging student goals for adult life;
- \* Exploration of funding resources;
- \* Connection with community networks beyond the disabilities community.

The Task Force is supported by the combined efforts of the Area 6 Board, the Department of Rehabilitation, Modesto City Schools, Stanislaus SELPA, and Valley Mountain Regional Center. Contact Area Board 6 at 209-473-6930 for more information, or check online at [www.areaboard6.ca.gov](http://www.areaboard6.ca.gov)

**Interested in employment and adult education resources?**

**Check out the links from the Resources for Adults page on the Area Board 6 website: [www.areaboard6.ca.gov](http://www.areaboard6.ca.gov)**

## **Local Artists Win 1st and 2nd Place In SCDD “Be Healthy and Enjoy Life” Poster Contest**



Artist Brenda Steward with her winning artwork *Healthy People Enjoying Life*

Brenda Steward and Steve Mattos won first and second prizes in this year's State Council on Developmental Disabilities poster art contest. Both artists live in San Joaquin County.

The annual poster art contest recognizes the creativity in all of us. The contest was open to all Californians with developmental disabilities.

A limited number of posters are still available through Area Board 6 at 209-473-6930.

Artist Steve Mattos with his winning artwork *Dancing in the Sunshine by the Sea*



(Cont from page 1)

### **10 Recommendations from SB 1270 Stakeholders**

6. Make sure support staff get the training they need to do a good job by putting together good trainers from across the state.
7. Get the word out about people with developmental disabilities who work and are involved in their communities.
8. For people who work and get SSI, let them keep more of the money they earn and health benefits.
9. Let Regional Centers pay for services that help people find and keep jobs and get out in the community to do things like everyone else.
10. Keep track of the work/employment situation of people with developmental disabilities and how they are involved in social and recreational activities in their communities.

***To view the complete report visit [areaboard6.ca.gov](http://areaboard6.ca.gov) or [www.scdd.ca.gov](http://www.scdd.ca.gov)***



**Congratulations!**  
**Ann Cirimele**  
**Family Resource Network**  
**Director**

Ann will be honored at the Supported Life 2007  
Inclusion Celebration  
Wednesday - October 3, 2007  
For more information  
Contact the Supported Life Institute  
916-567-1974

**Save the Date**  
**Disaster Preparedness**  
**One Day Conference**

*Planning and disaster preparedness  
for individuals with disabilities*

Friday September 21, 2007  
San Joaquin County Office of Education (SJCCE)  
2707 Transworld Drive  
Stockton CA  
For more information contact  
Area Board 6  
209-473-6930

**Visit our web site [Areaboard6.ca.gov](http://www.areaboard6.ca.gov)**

E-copies of our newsletter are available  
E-mail us at [ab6@scdd.ca.gov](mailto:ab6@scdd.ca.gov)  
with your request

**State Council on Developmental Disabilities**

**Area Board 6**

**2529 W. March Lane, Ste. 105 Stockton, Ca 95207 209.473.6930**  
**Visit us at - <http://www.areaboard6.ca.gov>**



**State of California**  
**State Council on Developmental Disabilities**  
**Area Board 6**  
2529 W. March Lane, Ste. 105  
Stockton, CA 95207-8270

*Address Correction Requested*



# *The Area VI Self Advocacy Info Sheet*

JUNE 2007

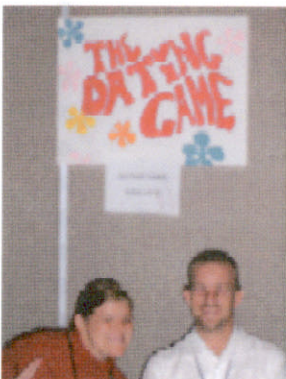
## **Self Advocacy Council VI Goes to Sacramento for the People First of California Annual Convention!**



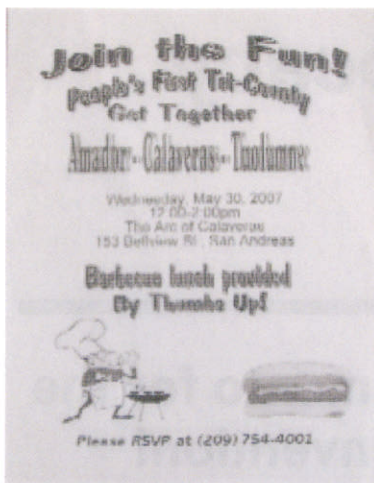
Pictured Left to Right - Jolene Bradford - SAC VI Coordinator, Jill Ames - Area VI Board Member, Terri & Gerald Smith, Sylvia, Donald Roberts, Krisi Franzone and Tim Cabral.  
(Not pictured - Eric Ybarra , Brad Putz, David Thomas, and Bruce Thomas)

The Self Advocacy Council VI members and two SCDD/ Area Board VI members attended the People First 2007 ***“Expanding Our Minds - Sessions that Educate Us”*** Convention in Sacramento. They weren't able to send all the SAC VI members, but hope to next year with the help of some fundraising efforts! We want to get more self advocates from Area 6 to the convention next year!

The Self Advocacy Council VI had a table at the agency fair, presented a workshop on Anger Management and also hosted the very popular Dating Game! It was a very full weekend and everyone did their part! Take a look at some of the pictures from the convention and mark your calendars for next year's convention! It will be June 13<sup>th</sup>, 14<sup>th</sup>, & 15<sup>th</sup> 2008.







## People First Tri-County Get Together Amador, Calaveras and Tuolumne Counties

This is the second get together with self advocates from the Tri-County areas. They met at The Arc in San Andreas. The Tuolumne County People First brought lots of goodies to share and BBQ'd. The other groups brought food items to share and The Arc provided a lovely setting outside for all to enjoy! Good food and fun! They hope to keep meeting regularly! Need more info? Call the Self Advocacy Council VI at 955-3624.



## The Self Advocacy Council VI Will be having a LOGO Contest...

The Self Advocacy Council VI would like to have a LOGO. They would like to have the LOGO designed by a self advocate or a self advocacy group from Amador, Calaveras, San Joaquin, Stanislaus, or Tuolumne Counties!! Individual and group designs are welcome!!

SO - think of a LOGO that would represent Area 6 self advocacy! Talk to your fellow self advocates and come up with a design!! You can send in your ideas to the Self Advocacy Council VI at 6333 Pacific Avenue-PMB 390 Stockton, CA 95207. More details to follow!

**Mark your calendar!!! Next Area Meeting for Self Advocates of Area 6!!**



**FRIDAY, AUGUST 3<sup>rd</sup>, 2007**

***We CAN'T use Quail Lakes Baptist Church this time because of their summer camp - so we are looking for another location and will get the word out ASAP.***

**QUESTIONS??? CALL  SAC VI at 955-3624**